

Posters

11. Nursing and Psychosocial Issues

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321 Effects of *Pseudomonas aeruginosa* (PA) status on health related quality of life (HRQoL) in patients with cystic fibrosis

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Objective: To compare the impact of *Pseudomonas aeruginosa* status on the CFQ-R respiratory domain scores in stable CF patients.

Methods: Stable (exacerbation free for ≥ 1 month) CF patients were recruited from the adult and paediatric CF centres of the Belfast Health & Social Care Trust. All patients completed the relevant age specific Cystic Fibrosis Quality of Life – Revised questionnaire (CFQ-R). CFQ-R respiratory domain scores range from 0 to 100 with higher scores indicating better function. Patients were classified as being either PA positive or PA negative according to the Leeds criteria.

Results: Data were collected from 100 patients (59M, 41F), mean(SD) age 23.8(14.0), range 6 to 78 years. A comparison of patients according to age, PA status and CFQ-R respiratory domain scores is displayed in Table 1.

Table 1. Comparison of patients according to age, PA status and respiratory domain scores

	N	Age		CFQ-R respiratory domain score	
		Mean (SD)	Range	Mean (SD)	Range
PA positive	32	26.3 (13.6)	7–78	69.5 (13.1)	38.9–91.7
PA negative	68	22.7 (14.2)	6–68	70.7 (15.5)	33.3–91.7

Analysis of responses using an independent t-test found no significant differences ($p=0.720$) in respiratory domain scores between PA positive and PA negative stable CF patients.

Conclusions: This finding is contrary to expectation. Further analysis will help determine this lack of difference.

322 Advances in transition: multi-level factors associated with adult achievement

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Objectives: With advances in CF care, patients are healthier and living into adulthood requiring an increased focus on successful transitions to adulthood. Yet CF patients have not realized professional and psychosocial achievement comparable to their improvement in health. To facilitate this process, CF centers are developing multidisciplinary transition programs. To better inform the development of these programs, we investigated factors, independent of health, that are associated with achievement.

Methods: Using a socio-ecologic framework, we developed a semi-structured interview to assess fifteen patients (25–35 yrs). Patients also completed established quantitative measures of self-efficacy and coping skills. Measures of lung function and nutritional status were gathered from medical records.

Results: Dominant themes from the interview suggest that a majority of patients have developed a sense of hopelessness, citing provider, parent, or self-expectations of limited adult life span and poor disease management, and lack of expectation to become productive adults. Secondly, the necessity to maintain healthcare through insurance or government assistance influences patients' pursuit of adult achievement e.g. employment, education, and marriage. We found no correlation between lung function and total self-efficacy scores or coping subscales.

Conclusions: Qualitative data indicate a constellation of psychosocial factors which influence multiple facets of developmental acquisition in adults with CF. Although larger scale investigations are warranted, data here indicate transition programs need to incorporate a biopsychosocial perspective into programming.

323 Transition to adult care – the qualitative experience of young people with cystic fibrosis

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Background: As life expectancy has improved, almost all young people with CF (YPWCF) transfer to adult care. How this event is experienced by these individuals has been little investigated via qualitative methods. A study using this research approach was conducted to explore the topic in-depth.

Methods: Participants were recruited from a UK adult CF centre. First appointments at this centre were observed by a researcher. YPWCF were also interviewed about their experiences of transferring. Framework analysis was used to manage and interpret data. Findings were discussed by paediatric and adult practitioners at an away-day.

Results: Observational data were collected from 12 YPWCF (6 males) and interviews conducted with 19 (12 males). Analysis identified an overarching concept of loss and growth within 3 themes: Contemplating age and gender norms, an outsider entering an established system and transfer bringing CF to the fore.

Discussion: Data highlighted the often demanding nature of first visits to the adult unit and the need for better preparation within paediatrics. Transfer involves positive and negative elements (growth and loss), both of which need to be addressed in planning transition, in individualised ways, depending on specific needs of each YPWCF. Findings have informed several user directed service improvements within local paediatric and adult teams.

324 A systematic review of the transition process for young people with cystic fibrosis

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Background: Transition of young people from child to adult healthcare services has become increasingly important as more are surviving into adulthood with chronic illnesses. There is limited empirical evidence in Ireland on how the process is experienced by young people with chronic illness; how it impacts on their health and well-being and how the transition process is managed by all stakeholders.

Methods: Phase 1 involved a systematic review of the research available, and we present the results in this paper. We searched the following databases (CINAHL, EMBASE, PsychINFO, Pubmed) individually using keywords from 2001 to 2011 which resulted in 520 papers. We removed non-research which resulted in 84 papers of which 62 were quantitative and 22 were qualitative studies. Of these, 7 qualitative and 10 quantitative studies focused on transition & cystic fibrosis.

Results: Despite the transition young adults continue to be interdependent upon their parents for support and assistance. Some parents resist the more marginal role they are expected to play in clinical consultations, which can lead to tensions in the young person/clinician/parent triad. Key facilitating factors were: relationship with clinician, clinician's attitude to transition and delivery of age appropriate care. Barriers included: treatment burden, accidental or purposeful forgetting of treatments, and lack of perceived benefit of treatments. Successful transitions programmes included orientation tours, information provision & familiar face in adult clinics.

Conclusion: Process is often poorly managed which has implications for healthcare professionals and parents.